ORIGINAL ARTICLE

Requirements for Vitiligo Registry Design in Iran: A Qualitative Content Analysis Study

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Abstract

Background: Vitiligo is a prevalent skin disorder that has significant biological and social consequences for the affected individuals. Therefore, appropriate measures should be taken to diagnose this disease and treat patients, and powerful information and monitoring systems, such as a registry, are required. This study aimed to identify the design requirements for vitiligo registry in Iran.
Methods: This qualitative study was conducted using a content analysis approach in 2020. In total, 9 dermatologists and health information management and medical informatics specialists working in Tehran, Shiraz, and Mashhad universities of medical sciences were interviewed. The participants were selected by a non-random purposive sampling method. The data were analyzed manually using thematic analysis approach.
Results: In this study, 7 major themes and 14 sub-themes were obtained regarding vitiligo registry design requirements. The major themes included registry objectives, structure, data sources, inclusion criteria, classification system, data quality control, and data reporting.
Conclusion: In total, 7 major themes and 14 sub-themes were identified to design the vitiligo registry. Developing a vitiligo registry based on these requirements could provide a better understanding of this disease, deliver high-quality services to patients across the country, and facilitate research on this disease.

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Introduction

Vitiligo is an acquired pigmentary skin disorder caused by the absence of pigment cells in the epidermis, leading to white macules on the body.[1] Vitiligo is usually associated with several autoimmune diseases, the most prevalent of which is thyroid disorders.[2] This disease is observed among different age groups.[3] Various studies have reported a wide range of estimates of vitiligo prevalence worldwide, ranging from 0.1% to 8%.[4] Most of the patients with vitiligo suffer from psychological disorders such as low self-esteem, high stress, and depression.[5] The autoimmune nature of this disease and its chronicity, as well as variable responses to treatment methods and its recurrence, reduce patients' quality of life (QOL).[6]

Accurate, timely, and accessible data play a vital role in providing policies and planning to develop and support health care services.[7] Various studies have been conducted on treatment methods used to treat these patients in Iran. However, there is no sufficient and coherent information about vitiligo and the affected individuals.[8, 9] The registry is an information system employed to collect, manage, and analyze data related to diseases. Registries are developed to achieve scientific and clinical goals and health policies and provide a real-world view of disease outcomes, safety, and effectiveness of health services if properly designed and implemented.[10]

Patient registry is considered important in the field of skin diseases. These registries aim to rapidly gather cutaneous manifestations and enable dermatologists and health care workers to have prompt access to the findings.[11, 12] Various registries have been provided for skin diseases, including psoriasis, alopecia areata, and ichthyosis.[11, 13, 14] Vitiligo registry could be employed to study the natural history of the disease in the population; identify risk factors, pathogenesis, and optimal treatments; and provide a better understanding of the disease progression and its impact on patients' quality of life (QOL).[15] It is necessary to identify the requirements for developing a registry to manage the vitiligo patient data. Given that these requirements have never been identified in Iran, the present study aimed to find out the requirements for vitiligo registry design in Iran.

Methods

This qualitative study was conducted using the content analysis approach in 2020. Semi-structured interviews were carried out with experts to identify the requirements for designing the vitiligo registry in Iran.

Participants

The participants included dermatologists and health information management and medical informatics specialists who were selected using a non-random sampling method and convenience case technique. Inclusion criteria were having educational and research experiences in the field of disease registry and working in Tehran, Mashhad, and Shiraz universities of medical sciences. Sampling continued until no new data were gathered from the interviewees and theoretical data saturation was achieved. Thus, 5 dermatologists, 3 health information management specialists, and 1 medical informatics specialist were interviewed.

Data Collection

The semi-structured interview guide regarding disease registry requirements was used. The interview guide, consisting of 7 questions, was prepared by reviewing the literature related to the research topic[15-18] and approved by 5 experts in the field of registry, including 2 dermatologists, 2 health information management specialists, and 1 medical informatics specialist (Appendix 1). The face and content validity of the interview guide was confirmed by conducting 3 preliminary interviews with the interviewees. The written informed consent form was obtained from all the participants, and they were assured that they were free to withdraw from the study at any time if they did not wish to continue their cooperation. Before conducting the interview, the research objectives were explained to the participants in person, and the interview's time and place were coordinated with them. A face-to-face interview was applied to collect the data. According to the interview guide, the interviewees were asked questions about the requirements for vitiligo registry design. Each interview lasted 45 minutes on average, and all the interviews were conducted by one researcher (a female PhD student in health information management). The interviews were recorded with the participants' consent. To avoid any potential mistakes in recording the voices, we recorded the interviews with two separate tape recorders and transcribed them immediately.

Data Analysis

The interview data were analyzed using the thematic analysis method, which consisted of 6 steps, including (1) becoming familiar with the data; (2) generating initial codes; (3) searching for themes; (4) reviewing themes; (5) defining and naming themes; and (6) reporting.[19] If required, the interviews were submitted to the participants to alter and/or reform any mistakes and add any required points. Given that the interview transcript was in the Persian language, the manual method, instead of the software, was used to encode and classify the data for improving creativity. At the end of this stage, the requirements for vitiligo registry design were identified.

Rigor

The Guba and Lincoln's four criteria, i.e., trustworthiness, confirmability, dependability, and transformability, proposed for confirming the reliability of qualitative studies, were used in data coding to improve the accuracy and precision of the research.[20] In doing so, the interviews were analyzed several times. In addition, the texts of the interviews were delivered to the participants for any required corrections or completion. Finally, the codes prepared from the interviews were given to one of the research colleagues and approved.

Results

Table 1 presents demographic characteristics of the participants. All the participants had a PhD degree, and their mean age and work experience were 49.4 and 17.9 years old, respectively. Analyzing the data revealed 14 sub-themes, which were classified into 7 major themes, including objectives, structure, data sources, inclusion criteria, classification system, data quality control, and data reporting.

Objectives

It is necessary to pay attention to the fact that the primary purpose of the registry system is to guide its design.

Table 1: Demographic characteristics of interviewees

Characteristics	No (%)	
Gender	Male	3 (33.3)
	Female	6 (66.7)
Age (years)	30>	0
	30-39	1 (11.2)
	40-49	4 (44.4)
	50≤	4 (44.4)
Work experience (years)	5>	0
	5-9	3 (33.3)
	10-14	0
	15≤	6(66.7)
City	Tehran	5 (55.6)
	Shiraz	2(22.2)
	Mashhad	2(22.2)

These goals determine the extent to which these programs should be developed, what information they should collect, who the stakeholders are, and how information should be collected; the participants stated that "determining the incidence and prevalence of vitiligo in the society" (P3) and managing patients' medication are among the most important objectives of creating a registry in the country, which could improve the structure of the health system as well as health planning" (P1).

The interviewees believed that "since evaluating and improving the quality of services and care provided to patients (P2) as well as developing and promoting clinical research on vitiligo are of great importance, these parameters should be considered as the important objectives of creating the vitiligo registry" (P4). Moreover, "this registry may be created to develop disease prognosis models and forecast equipment and resources" (P9).

Structure

Structure was another major theme, which included sub-themes of responsible organization, type of registry system, and method of organizing registry centers. Most of the interviewees described Ministry of Health as the responsible organization. "I believe that it would be better if Ministry of Health takes the main responsibility for creating this registry nationally at the macro level." (P6) "Since University of Medical Sciences and its faculties are ultimately responsible for manpower training, the tutelage should be entrusted to Ministry of Health. Preferably, the main responsibility should be given to Ministry of Health; cooperation should be established between the registry office of the ministry and registry offices set up in medical universities and research centers of hospitals, and the ministry should be responsible for supervision." (P7)

Most of the interviewees described the type of registry system as population-based: "It would be better if the registry includes all the diseases in a population, such as self-reported diseases as well as those that have been diagnosed either clinically or through screening. Population-based registry requires participation of all skin care providers in different parts of the country to be sufficiently comprehensive." (P3)

The method of organizing registry centers was another sub-theme. The interviewees emphasized the necessity of paying serious attention to the centralized governance: "I believe that the method of organizing registry centers should be considered in a centralized manner in order to create the registry nationally." (P8).

Data Sources

The participants maintained that hospitals, dermatology centers, dermatologists, pathology centers, and electronic health record system could be used as data sources: "I believe that hospitals are among the most important data sources in the disease registry. However, in most cases, they do not oblige themselves to collect data" (P2); also, Dermatology centers as well as specialists working there are considered important data sources in the registry. These data sources play a key role in the complete and valid registration of data" (P4). According to the participants, "Although the data recorded in the electronic health record are primarily collected for purposes other than the registry, they could be used as a good secondary source. Since these data are collected electronically, they could be easily accessed and used in the registry without obtaining legal permission." (P7)

Data and Inclusion Criteria

This major theme led to the identification of the sub-themes of registry inclusion criterion, method of describing data elements, and data collection method. Some of the interviewees regarded disease confirmation at the pathology stage as the registry inclusion criterion: "Vitiligo sampling is not routinely performed. However, it is prescribed by the physician in cases of differential diagnosis. The patients confirmed at this stage should be included in the system." (P2)

In most cases, vitiligo could be easily diagnosed based on clinical findings and the physician could diagnose the disease by taking a history and examining the patient. "Patients who have been diagnosed with vitiligo by a dermatologist and those who are receiving treatment should be included in the system." (P3)

Regarding the method of describing data elements, most of the interviewees emphasized using a data definition document and dictionary, which include definitions of terms and coding: "In my opinion, a data dictionary is important as it unifies data definitions across the country, so that all people have the same perception of the data. We should provide common definitions and coding for vitiligo terms and use them in our registry throughout the country." (P6) "A standard data set should be created to collect and report data in a standard and integrated manner in the registry. These definitions could improve data matching, which is considered an important step for sharing the data collected in different health centers and is supposed to be used in the future." (P7)

Regarding the data collection method, most of the participants recommended using both active and passive methods depending on the situation and facilities: "The hybrid method should be used according to the conditions and facilities. The data could be passively collected, i.e., the data should be collected and transmitted by data producers who are the source data providers as well." (P4) "The data could also be actively collected. In this method, the data are collected and transmitted by registry experts." (P5)

Classification System

All the participants emphasized using the International classification of Diseases, Tenth Revision (ICD-10) and International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM). "Using ICD-10 and ICD-9-CM classification systems as accurate tools for disease reporting should be considered in the registry design to compare the data efficiently." (P7). Moreover, these systems facilitate the possibility of comparing the data nationally and internationally." (P8)

Data Quality Control

Regarding preventive control, the participants stated: "Appointing a person to control the system quality as well as preparing the Minimum Data Set (MDS) and using it at the national level" (P3) and "referring to health care institutions and conducting internal and external audits either randomly or with prior coordination" (P6) are among the tasks that could be performed to improve the registry quality.

"Using closed-form expressions, according to which the registrar selects only the correct patient-related option" (P9) as well as "programming the computer for double-checking the validity of the data entered into the system, properly designing standard forms for complete data collection, continuously updating report forms, using multiple-choice questions on computer screens, and enabling sound or verbal notifications to alert users while recording data" (P8) are very helpful. Moreover, the participants believed that several scanning control methods should be used: "The system should provide us with exceptions and registration errors in printed form." (P1)

Furthermore, they emphasized the importance of using editor control methods: "In my opinion, teaching users to enter data correctly is considered the first step for improving the quality of data inclusion in the registry. If a user constantly makes mistakes in registering data, we should deal with them professionally and create an opportunity to complete the report or correct potential errors." (P4)

"It is often observed that the physician/documentarian either does not enter the data supposed to be entered in the registry or enters them incorrectly. In this case, they should be warned." (P7) "We should plan to identify potential errors and missing data, report and delete duplicate data, and recognize data with unauthorized values. The system administrator should periodically update the system after fixing the problems." (P2)

Data Reporting

This major theme led to the identification of sub-themes of data transmission time limit, data transmission method, reporting method, notification system, and confidentiality practices. Most of the participants believed that reporting was necessary at different times based on the center level: "Reporting should be done at different times as needed, which may happen monthly or quarterly depending on the type of center. A specific process could not be determined and reported to the centers." (P4)

Regarding data transmission method, most of the interviewees reported using both electronic and paper structures simultaneously as the method of transmitting the data: "It is better to use both electronic and paper structures simultaneously to send data. It should be noted that the reports, whether in paper or electronic form, should be submitted in a specific format." (P3)

Regarding the reporting method, the interviewees stated: "Reporting should be done to increase decision makers' awareness by following information disclosure rules." (P1)

Almost all the interviewees agreed on the notification system: "I think that using specialized and scientific journals and periodicals would be the best option because most people have easy access to them." (P5)

Table 2: Major themes and sub-themes of vitiligo registry requirements in Iran

Major theme	Sub-theme	Final codes
Objectives		Determining the incidence and prevalence of vitiligo in the society
		Managing medication used by vitiligo patients
		Evaluating and improving the quality of services and care provided to vitiligo patients
		Developing and promoting clinical research on vitiligo
		Developing disease prognosis models and forecasting equipment and resources
Structure	Responsible organization	Ministry of Health and Medical Education
	Type of registry system	Population-based
	Method of organizing registry centers	Centralized
Data sources		Hospitals
		Dermatology centers
		Dermatologists
		Pathology centers
		Electronic health record system
Data and inclusion criteria	Registry inclusion criterion	Patients diagnosed with vitiligo and confirmed by a dermatologist
		Patients with active vitiligo under treatment
		Vitiligo patients confirmed in pathology examination
	Method of describing data elements	Data definition document and data dictionary
	Data collection method	Using both active (collecting and transmitting data by registry experts) and passive (collecting and transmitting data by data producers) methods depending on the situation and facilities
Classification system		International Classification of Diseases, Tenth Revision (ICD-10)
		International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM)
Data quality control	Preventive control	The presence of a specific person for controlling data quality in the system
		Preparing the Minimum Data Set (MDS) and using it at the national level
		Referring to health care institutions and conducting internal and external audits either randomly or with prior coordination
		Programming the computer for double-checking the validity of the data entered into the system
		Properly designing standard forms for complete data collection
		Continuously updating report forms
		Using multiple-choice questions on computer screens
		Using closed-form expressions, according to which the registrar selects only the correct patient-related option
		Enabling sound or verbal notifications to alert users while recording data
	Scanning control	Printing the list of registry errors as the error report by the system
		Printing the exception report by the system
	Editor/modifier control	Teaching users to enter data correctly into the system
		Dealing with users professionally and warning the physician/documentarian about errors and lack of necessary data
		Identifying potential errors
		Checking for missing data
		Reporting and deleting duplicate data
		Identifying data with unauthorized values
		Updating the system periodically after fixing the problems by the system administrator
		Providing an opportunity for users to complete reports or fix potential errors
Data reporting	Data transmission time limit	Reporting at different times based on the center level
	Data transmission method	Simultaneous use of both electronic and paper structures as needed
	Reporting method	Reporting to increase the awareness of decision makers by following information disclosure rules
	Notification system	Specialized journals
		Periodic reports
		Scientific journals
	Confidentiality practices	Authentication and access control of users when logging in using a unique ID and password
		Developing data transmission guidelines and following them
		Data backup daily
		Predicting data recovery programs in crisis situations
		Using protection methods such as a firewall on web-based systems
		Equipping desktop systems with antivirus software
		Identifying attempts made to gain unauthorized access to the system
		Appointing a person to be in charge of security when creating the registry system
		Establishing an information disclosure committee to oversee the implementation of information disclosure policies

All the interviewees believed that maintaining confidentiality is among the requirements of the system: "The responsibility of registry security should be assigned to a person who specializes in network security. We should establish a committee called "information disclosure committee" to oversee the implementation of information disclosure policies." (P7) "We should provide this committee with some instructions to protect the data. Moreover, we must prepare data transmission guidelines and declare that everybody should follow these guidelines." (P9)

Access to the system and data should be determined according to the role of each person. "Only authorized individuals should have access to the data. The user should be authenticated with a unique user ID and password defined by the system administrator to be able to enter the registry." (P2)

"We should identify the attempts made to gain unauthorized access to the system" (P8). Another interviewee said: "All systems should be equipped with a firewall, and a strong antivirus should be installed on all the systems linked to the registry and updated regularly. We should ask all the users to back up their data daily for maintaining our registry data and plan for data recovery in times of crisis." (P6)

Table 2 presents the requirements identified in this study for vitiligo registry design in Iran.

Discussion

This study was conducted to identify the requirements for vitiligo registry design in Iran. The identified requirements included 7 major themes and 14 sub-themes. The major themes included objectives, structure, data sources, data and inclusion criteria, classification system, data quality control, and data reporting.

In one study (2017) conducted in the University of Texas Southwestern Medical Center, Dallas, a registry was created to collect vitiligo patient data.[15] The system design requirements were not completely reported in this registry. Moghaddasi et al. (2019) proposed a psoriasis registry model to identify the requirements for creating this system in Iran.[18] According to experts, 7 requirements were identified for vitiligo registry design, which was consistent with our work. However, the number and details of data elements varied due to the development goals of each system.

Well-defined objectives could determine data collection and analysis processes and prevent low-value-added data collection that could degrade the registry quality.[10] Dermatologic registries could be used to identify a set of factors influencing the choice of treatment and drug efficacy.[21-23] The objectives of this registry system were somewhat consistent with those of the above studies.

Pillay et al. (2008) examined the psoriasis registry structure and introduced the Ministry of Health as responsible for this system at the national level. Clinical research center, association of dermatologists, and pharmaceutical companies were also reported to be accountable for this registry system.[24] The results of this study are consistent with our research. In the present work, the experts considered the Ministry of Health and Medical Education as responsible for this system. Considering that the Malaysian Psoriasis Registry (MPR) and vitiligo registry discussed in this study were both population-based, they were consistent in this respect.

In designing the alopecia areata registry, dermatology centers, dermatologists, and patients have been regarded as data sources.[25] However, in the present study, the experts considered hospitals, dermatology centers, dermatologists, pathology centers, and an electronic health record system as data sources. Hospitals are among the most important data sources to collect data in the disease registry, and specialists working in dermatology centers play a key role in the complete and valid registration of data. Data recorded in the electronic health records are collected electronically and could be easily accessed and used in the registry while obtaining legal permission. The inclusion criteria in the vitiligo registry were patients diagnosed with vitiligo and confirmed by a dermatologist, patients with active vitiligo under treatment, and vitiligo patients confirmed in the pathology examination. The inclusion criteria in the psoriasis registry system were patients with moderate or severe psoriasis who were undergoing systemic or biological treatment,[22] which was not in line with the present study. Patients approved in the pathology examination should be included in the system because this method is a valuable diagnostic criterion.

In one study, a data definition document was developed to accurately describe data elements in Malaysian Psoriasis Registry (MPR), which served as a basis for collecting data. Accordingly, a new registry as well as a strong source of funding were created for development of MPR.[18] Similarly, in the present study, a data definition document and data dictionary were proposed with the consent of most experts to describe data elements.

In the alopecia areata registry system, International Classification of Diseases, Ninth Revision (ICD-9) and International Classification of Diseases, Tenth Revision (ICD-10), were employed as classification systems. The results showed this system had higher diagnostic accuracy due to using the classification system, and these accurate diagnoses could be used in the future to support epidemiological studies and determine disease burden, comorbidities and management patterns.[26] International Classification of

Diseases, Tenth Revision (ICD-10) and International Classification of Diseases, Ninth Revision, Clinical Modification (ICD-9-CM) were the classification systems recommended by the experts for the vitiligo registry. Using classification systems as accurate tools for disease reporting should be considered in the registry design to compare the data efficiently. Moreover, these systems facilitate the possibility of comparing the data nationally and internationally.

In another study (2018), four techniques, including required items, condition determination, input data validation, and help texts, were employed to ensure the quality of data when entering the system.[27] In the present study, a wider range of methods was proposed to control the data quality.

Naldi (2009) and Ingelfinger (2004) emphasized the necessity of maintaining confidentiality and security of registry data and assigning a unique identifier to each patient to avoid duplicate registration and confusion.[16, 17] In the present study, the experts did not approve of assigning unique identifiers to patients to maintain confidentiality and security.

Limitations

The limitation of this study was the collection of requirements for vitiligo registry design only by an interview with 9 dermatologists and health information management and medical informatics specialists who had educational, executive, and research experiences in the field of registry; they were interviewed at Tehran, Shiraz, and Mashhad universities of medical sciences. Hence, the results may not reflect all specialist' perspectives from different healthcare settings across the country. In addition, the results may not be generalizable to the registries of other countries.

Conclusion

This study indicated the most important requirements for vitiligo registry design. To optimize the infrastructure of Iran's vitiligo registry system, the most important requirements, such as objectives, structure, data sources, data and inclusion criteria, classification system, data quality control, and data reporting mechanism, should be determined. Decisions made based on the recorded data in this registry could provide high-quality services to vitiligo patients nationwide and facilitate research on this disease.

Authors' Contribution

ZA: investigation, visualization, methodology, formal analysis, and writing the original draft. RS: methodology, validation, formal analysis, writing, reviewing and editing. PB: conceptualization, methodology, writing, reviewing, and editing. AB: conceptualization, writing, reviewing, and editing. AS: conceptualization, methodology, writing, reviewing and editing, and supervision. All authors read and approved the final manuscript.

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Ethical Code

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References

1 Seneschal J, Boniface K, D'Arino A, Picardo M. An update on Vitiligo pathogenesis. Pigment cell & melanoma research. 2021; 34(2):236-43. doi: 10.1111/pcmr.12949.

2 Sandru F, Carsote M, Albu SE, Dumitrascu MC, Valea A. Vitiligo and chronic autoimmune thyroiditis. J Med Life. 2021; 14(2): 127-30. doi: 10.25122/jml-2019-0134. PMCID: PMCID:8169145. PMID: 34104234.

3 Das S, Kaur S. Nano-Lipid-Carriers for the Treatment of Vitiligo: A Recent Update, Pathophysiology and Mechanism of Drug Delivery. Current molecular pharmacology. 2021; 14(3): 306-20.doi: 10.2174/1874467213999201109220714.

4 Tang L, Li F, Xu F, Yan S, Zhou J, Li J, et al. Prevalence of vitiligo and associated comorbidities in adults in Shanghai, China: a community-based, cross-sectional survey. Annals of palliative medicine. 2021; 10(7):8103-11.doi: 10.21037/apm-21-1738.

5 Chan MF, Chua TL, Goh BK, Aw CWD, Thng TGS, Lee SM. Investigating factors associated with depression of vitiligo patients in Singapore. Journal of clinical nursing. 2012; 21(11-12):1614-21. doi: 10.1111/j.1365-2702.2011.03777.x.

6 Khaitan BK, Sindhuja T. Autoimmunity in vitiligo: Therapeutic implications and opportunities. Autoimmunity reviews. 2022; 21(1): 102932. doi: 10.1016/j.autrev.2021.102932.

7 Mattingly R. Management of health information: functions and applications: Delmar Pub; 1997.

8 Aghaei S, Safaee Ardekani G. Topical immunotherapy with diphenylcyclopropenone in vitiligo: a preliminary experience. Indian Journal of Dermatology, Venereology & Leprology. 2008; 74(6).doi: 10.4103/0378-6323.45108. PMID: 19171989.

9 Hallaji Z, Ghiasi M, Eisazadeh A, Rayati Damavandi M. Evaluation of the effect of disease duration in generalized vitiligo on its clinical response to narrowband ultraviolet B phototherapy. Photodermatology, photoimmunology & photomedicine. 2012; 28(3):9-115.doi: 10.1111/j.1600-0781.2012.00648.x.

10 Gliklich RE, Dreyer NA, Leavy MB. Registries for evaluating patient outcomes: a user's guide. 2014.

11 DiMarco G, Hill D, Feldman SR. Review of patient registries in dermatology. Journal of the American Academy of Dermatology. 2016; 75(4): 824-9. doi: 10.1016/j.jaad.2016.03.020.

12 Amin M, Lee EB, Bhutani T, Wu JJ. Review of European registries for psoriasis. Journal of Dermatological Treatment. 2019; 30(3): 227-36. doi: 10.1080/09546634.2018.1506084.

13 Shi Q, Duvic M, Osei JS, Hordinsky MK, Norris DA, Price VH, et al., editors. Health-related quality of life (HRQoL) in alopecia areata patients—A secondary analysis of the National Alopecia Areata Registry Data. Journal of Investigative Dermatology Symposium Proceedings; 2013: Elsevier. doi: 10.1038/jidsymp.2013.18.

14 Fleckman P. The National Registry for Ichthyosis and Related Disorders Will Cease Operation after 2012. The Journal of Investigative Dermatology. 2012; 132(7): 1745.

15 Hinojosa JA, Pandya AG, editors. The importance of patient registries in skin of color. Journal of Investigative Dermatology Symposium Proceedings; 2017: Elsevier. doi: 10.1016/j.jisp.2017.01.002.

16 Naldi L, Chatenoud L. Registry research in dermatology. Dermatologic clinics. 2009; 27(2): 185-91. doi: 10.1016/j.det.2008.11.004.

17 Ingelfinger JR, Drazen JM. Registry research and medical privacy. Mass Medical Soc; 2004. p.1452-3. doi: 10.1056/nejme048027 . PMID: 15070797.

18 Moghadasi Cheveinli M, Z MS. The comparative study of registry system of psoriasis in Iran and selected countries and presenting a proposed model for Iran: Shiraz University of Medical Scienes, School of Management and Medical Information; 2019.

19 Nowell LS, Norris JM, White DE, Moules NJ. Thematic analysis: Striving to meet the trustworthiness criteria. International journal of qualitative methods. 2017; 16(1): 1609406917733847. doi: 10.1177/1609406917733847.

20 Guba EG, Lincoln YS. Competing paradigms in qualitative research. Handbook of qualitative research. 1994; 2(163-194): 105.

21 Driessen R, Boezeman J, Van de Kerkhof P, De Jong E. Three-year registry data on biological treatment for psoriasis: the influence of patient characteristics on treatment outcome. British Journal of Dermatology. 2009; 160(3): 670-5. doi: 10.1111/j.1365-2133.2008.09019.x.

22 Augustin M, Spehr C, Radtke MA, Boehncke WH, Luger T, Mrowietz U, et al. German psoriasis registry PsoBest: objectives, methodology and baseline data. JDDG: Journal der Deutschen Dermatologischen Gesellschaft. 2014; 12(1): 48-57. doi: 10.1111/ddg.12233.

23 Kimball A, Leonardi C, Stahle M, Gulliver W, Chevrier M, Fakharzadeh S, et al. Demography, baseline disease characteristics and treatment history of patients with psoriasis enrolled in a multicentre, prospective, disease-based registry (PSOLAR). British Journal of Dermatology. 2014; 171(1): 137-47. doi: 10.1111/bjd.13013.

24 Pillay M, Noor Hisham A, Zaki Morad M, Lim T, Jamaiyah H, Jaya Purany S. Patient registries in Malaysia and the role of the Clinical Research Centre of the Ministry of Health. Med J Malaysia. 2008; 63 (Suppl C): 1-4.

25 Duvic M, Norris D, Christiano A, Hordinsky M, Price V, editors. Alopecia areata registry: an overview. Journal of Investigative Dermatology Symposium Proceedings; 2003: Elsevier. doi: 10.1046/j.1087-0024.2003.00814.x.

26 Lavian J, Li SJ, Lee EY, Bordone LA, Polubriaginof FC, Christiano AM, et al. Validation of case identification for alopecia areata using International Classification of Diseases coding. International Journal of Trichology. 2020; 12(5): 234. doi: 10.4103/ijt.ijt_67_20.

27 Hoeijmakers F, Beck N, Wouters MW, Prins HA, Steup WH. National quality registries: how to improve the quality of data? Journal of thoracic disease. 2018; 10 (Suppl 29): S. 3490. doi: 10.21037/jtd.2018.04.146. PMCID: PMC6230825 . PMID: 30510784.

Appendix 1

Semi-structured questions used in the interview guide are as follows:

1. In your opinion, what are the most important objectives for designing the vitiligo registry in Iran?
2. In your opinion, what are the most important structures for designing the vitiligo registry in Iran?
3. In your opinion, what are the most important data sources for designing the vitiligo registry in Iran?
4. In your opinion, what are the most important data and inclusion criteria for designing the vitiligo registry in Iran?
5. In your opinion, what is the most important classification system for designing the vitiligo registry in Iran?
6. In your opinion, what are the most important data quality control methods for designing the vitiligo registry in Iran?
7. In your opinion, what are the most important data reporting methods for designing the vitiligo registry in Iran?